Co-production and co-producing research with children and their parents

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This commentary is part of a series on practical research ethics and focuses on 'co-production'. Increasingly, research funders are asking for co-produced research. Here, we clarify this concept, and the opportunities and practical challenges it can bring to paediatric research. Our commentary complements Preston et al's article on how to involve children and young people in research.

What is co-production?

Co-production is sometimes thought of as innovative but it has been around for a good while - even longer if you look for the concept rather than the term itself. *Practically*, it means researchers and patients prioritising and/or designing research together from the start.

Co-production *theory* argues that knowledge arises from lived experiences, as well as meticulous scientific work, which in turn is influenced and constructed by peoples' lives and interactions: "the ways in which we know and represent the world are inseparable from the ways in which we choose to live in it" (p2).[1] In the health context, knowledge is created in the interaction between science, and the social world outside the laboratory, the hospital and the university.

This understanding of knowledge informs the *practice* of co-production, which we focus on here. Central to this is research as a shared enterprise.

A good example is the ground breaking research funded by the French Muscular Dystrophy Association (AFM-Téléthon: http://www.afm-telethon.com/). AFM- Téléthon was established in 1958 by parents of children with muscular dystrophy, and has remained a patient-led organisation and a leading funder of research into the cure and care of neuromuscular conditions. In this organisation, patients and parents hold several roles. They are political agents working to improve the treatment of muscular dystrophy. They are active collaborators shaping the research. They volunteer as participants in research studies. For example, when little was known about this condition, parents played an instrumental role in evidencing the impact of muscular dystrophy, by filming their children over time. Parents and adult patients hold strategic positions within the organisation, directing what research is prioritised. Researchers are in charge of ensuring the scientific quality of the research, while patients and parents help shape the research so that it is relevant to their experiences, and their knowledge gained through those experiences.[2]

FM- Téléthon is a story of teamwork by people with a shared interest (patients, parents, clinicians and researchers) and research outputs which could not have existed without this teamwork.[2] This is co-production.

Why co-production?

There are many reasons why funders ask for co-produced research. The most common argument is that research should respond to needs of patients and healthcare providers – both professionals and family carers.

All health research is complex and can lead to complex interventions. Even when a study is testing the use of one particular drug in relation to one well-defined patient group, the routine hospital setting is a complex environment which can impact on how (and whether) the treatment is provided, and how patients respond to taking it. Because of the complexity of health services, and the challenges of patients with multiple conditions, it is increasingly recognised that health researchers and clinicians cannot on their own produce practice-relevant studies.[3] To improve the relevance of studies we need to involve a whole range of people who work in health services provision, including commissioners of services and patients.

An important driver for co-production is reducing research waste.[4] This involves the effective use of limited resources, and producing research findings that address patients' needs. Health research has long been driven by the priorities of scientists and industry, who may second-guess, or disregard patients and carers' priorities.

In spite of convincing examples where co-production has contributed to ground-breaking cure and care[2 5], most health research is not yet co-produced. The standard research team set-up is a principal investigator who leads a team of research experts to investigate a problem that they, or in the case of commissioned calls, their funders consider important and researchable. Relatively recent pressure from funders for patient involvement means that parents are increasingly invited to comment on patient information leaflets or questionnaires. They are less likely to influence *what* is researched, despite the work of the James Lind Alliance in the UK leading to an increased number of co-produced calls for research (http://www.jla.nihr.ac.uk/). Co-production can be seen as an in-depth form of involvement, because it means working actively *with* parents and children.

What are children capable of doing?

If we are to work *with* children to prioritise and design research we need to ask ourselves what we believe children are capable of. Health professionals and educators are used to bearing in mind lists of developmental stages setting out what the average child is likely to be able to do at a certain age and stage. For researchers, it might be more helpful to start with what we lose if we do not work closely with children and their parents whatever their assumed capacity might be:

- Children, even those under the age of 10, partner with their parents in producing and maintaining good health at home.[6] Unless we work with them, we miss these perspectives in our research: what it's like to live with a condition at school and in social activities, and how this influences how children, their siblings and their parents engage in treatment and care.
- All research needs to be communicated. The UK government website www.gov.uk asks contributors to write for a 9 year old reading age and if you google 'average reading age UK', 9 years old comes up. Working with actual 9 year olds will help you improve your communication skills.
- Parents who go to school concerts and nativity plays are sometimes surprised by what their children can do. By working only with parents you risk making assumptions in your research about what children think and do.
- Emerging evidence from technology suggests that children may be more creative and less constrained than adults, thereby pushing for new solutions.[7]
- Children, like adult patient partners, can learn about research and contribute to it.[8-10]

Characteristics of co-produced research

In co-production people with different experiences of healthcare and treatment define the parameters of a study together.[11] Patients traditionally equate to participants in research, rather than active partners in planning research. For this reason it is common amongst researchers to conflate partnership with patients (co-production) with study designs that collect patients' views and experiences (for example qualitative interview studies). It is therefore worth noting that:

- Co-production is not a research method. Any study design including clinical trials or lab-based studies can be co-produced.
- Co-produced research can be participatory and train children or parents in collecting data, but it doesn't have to be.
- For research to be co-produced, healthcare providers, children and their parents need to be involved in shaping the research based on shared experiences.

INVOLVE is the UK national advisory organisation for patient involvement in health research. They have published guidance on co-production[12] which lists five principles: 1) sharing power; 2) including all perspectives and skills; 3) respecting and valuing knowledge of all when working together; 4) reciprocity; 5) building and maintaining relationships. These principles may seem a long way from where we are currently. Below we propose how we can start working towards them.

a) Sharing power

In reality power can only be shared if the powerful give something up, which usually means that power is bestowed rather than shared. The INVOLVE guideline defines 'sharing power' as 'shared responsibility' for the research. Power without responsibility and responsibility without power are both problematic. Our main point is that children and their parents (who already carry major responsibility for their children, often with insufficient power to influence) may be sceptical about taking on additional responsibilities.

How we can implement this in child health: We can start by acknowledging that children can contribute meaningfully to child health research. We can make efforts to understand children's priorities for care and treatment, and build research questions around these. For example, either as parents and citizens, or in our professional roles as teachers or healthcare workers, we can run research clubs in primary schools or community centres where children can learn about research and formulate ideas with researchers. When we hear about children's priorities, we can take these ideas seriously and compare them to our own priorities, and those of parents and providers. Hearing what children tell us, and asking questions to understand better what they are saying, we can connect priorities and shared interest across stakeholder groups.[13]

b) Including all perspectives and skills

The INVOLVE guideline states that in co-production, all necessary views, experiences, skills and knowledge should be included on the research team.

How we can interpret this in child health: It may not be practical or desirable to have children actively involved in research team meetings. We need alternative options for involving children in shaping the research. Meetings for and with children can be organised at weekends, or as an optional activity before, during or after hospital stays. Children can be invited with their parents, and these meetings can focus on the unique expertise that children and their parents bring, rather than technical research decisions. For example, is this research going to be important to patients and their families? If not, can we change it or add to it so that it is? Tools

already used by researchers designing studies, such as PICO or SPICE[i], can be used to enable conversations about the focus of the research. What is said in these meetings can be brought into discussions held in the research team to be integrated into ongoing research plans. Unless this happens (or the information is only used if it resonates with what we plan anyway) it is an unethical use of everyone's time.

c) Respecting and valuing the knowledge of all those working together on the research

Researchers and clinicians tend to prefer peer reviewed knowledge to what is sometimes dismissed as anecdote. We have a long way to go before children are considered knowledgeable.

How we can interpret this in child health: In our daily lives many of us observe how wise children can be, irrespective of their age. This is borne out in research, which has shown that children often know more than adults give them credit for[6 14 15] Over the years, childhood researchers have built up a set of tools and methods[16] for speaking with children in a research context, some of which can be useful in co-production. Research teams will usually include childhood researchers or healthcare professionals with paediatric training who can take responsibility for working with children and their parents and help the wider research team to do so. Children and parents who have a positive experience of co-producing research are more likely to be encouraged into further involvement. It is also important to be aware that co-produced research can be led by researchers and usually is. Researchers hold the ring on the research governance, research methods and make sure the study questions and methods hang together.[17]

d) Reciprocity

Co-production should be meaningful and beneficial to everyone involved.

How we can interpret this in child health: Working with children on their terms is likely to make meetings more enjoyable for them as well as us. Feedback is essential, even if it sometimes means admitting that the research ran aground because of lack of funds or failure to recruit. Payment to children is a thorny issue and vouchers are often used.[18] Travel and other expenses related to attending meetings need to be fully reimbursed. Providing refreshments at meetings can make people feel valued and respected, as well as breaking the ice.

e) Building and maintaining relationships

Researchers wanting to co-produce research need capacity, primarily time, to find organisations or individuals willing to work with them, and time to maintain these relationships.

How we can interpret this in child health: Given the patchy infrastructure to co-produce research with children, researchers might need to start with this stage. Building relationships can enable implementation of the other standards. For example, if a researcher sets up a research club at a local primary school, research ideas might start to flow from the children attending. The initial meetings might be challenging to run, but over time the researcher will develop skills that improve their way of communicating. Slowly, as we learn to speak about our research in new ways, we develop relationships that enable us to work collaboratively with people who are not researchers themselves. Researchers can also initiate relationships with some of the young people's participation groups run by charities and some NHS and local government agencies.

How can we make co-production with *children* a reality?

Some research teams have established young people's advisory groups co-ordinated and led by an adult facilitator. The young people's groups meet and discuss aspects of the research and their advice fed back to the research teams.[19 20] In other studies young people have been part of shaping the research, deciding how to do it, and doing it.[21 22]

As regards younger children, there are examples where they have designed and carried out research enabled by a researcher working in a primary school, teaching them about research methods, and giving children the time to plan and conduct studies on their own.[23] There are other examples where researchers worked with children in a child-led way to understand the world from their perspectives.[14 24] The challenge in co-production is to enable a space where children and adults *jointly* design research projects and plans.

Some research teams may not be in a position to incorporate the INVOLVE standards into their way of working, but it is important to recognise small steps to involving children and parents can be taken and that these may enable in-depth co-production later on. Informal involvement can mean attending an existing group, at school or hospital, and asking people for their views on the research you would like to do. In order to co-produce with children and their parents we need to exercise our skills in "listening to children: and hearing them".[13] This we can do in our day-to-day life as well as in organised settings.

In co-production we also need to remember that we are not collecting research data from parents and children but working with them as partners in research. Parents and children are asked to draw on individual experiences to inform the research. They can choose if they prefer to provide advice without going into details of these experiences. To steer meetings towards talking about the research the following can be helpful:

- Clear role descriptions, and a timeframe for partnership work
- Meetings held outside the hospital setting if this is practical for children and parents
- Using tools from the research world to frame discussions. For example, discussing one or more components of the design in the form of PICO (population – intervention – comparison – outcomes), or asking children and their parents to consider how well a questionnaire captures their experiences. Starting conversations about something that can be used in research will lead to conversations about the research design and implementation.

In conclusion

This article discusses how child health researchers can take a pragmatic approach to co-production. Children's social position in society, and restraints which limit their ability to actively participate in public life, mean that researchers first need to practice talking to children and parents about health research. We need to challenge ourselves to take children seriously, and consider seriously their perspectives on healthcare and treatment. Childhood researchers have published methods for how to talk with children. We need to learn from this literature, practice these tools and then work up new tools for how to work *with* children and their parents in designing research.

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[i] PICO stands for Population, Intervention, Comparison, and Outcome. SPICE stands for Setting, Population or Perspective, Intervention, Comparison, and Evaluation. These are often used to structure a research idea in applied health research.